
Children's Special Health Internal Policy/Statement Hereditary Clotting Factor Deficiencies (Bleeding Disorders)

Description

Hemophilia A (Factor VIII deficiency) and Hemophilia B (Factor IX deficiency) are the most common severe inherited coagulation factor deficiencies. Their symptoms are virtually identical; clot formation is delayed thus allowing continued bleeding. Hemophilia C refers to the bleeding disorder associated with reduced levels of Factor XI and the bleeding is more moderate than A and B. von Willebrand Disease is a common hereditary bleeding disorder.

Diagnostic Criteria

 Blood tests such as: APTT, platelet count, fibrinogen (Factor I), activated clotting time, prothrombin time, thrombin time, quantitative Bethesda assay, and specific assay for Factor VII, VIII, Factor XI, and Factor IX

CSH Coverage

- Only **providers** listed on the Eligibility Letter will be paid
- Labs/Tests must be performed by a Wyoming Medicaid provider
- Well Child Checks (coverage limited to Pediatrician) according to AAP Periodicity Schedule
- Medications
 - Anti-hemophiliac Replacement Therapy of the different Factors
 - Plasma
- Equipment/Supplies
 - None

Contact CSH for questions regarding additional medication and/or equipment/supplies

Minimum Standards of Care/Care Coordination

Refer to Care Coordination Manual, Ch. 3, Pg. 8, Child and Family Assessment

- Perform **Nursing Assessment** with detailed focus on the following:
 - Assess any signs and symptoms of a bleed (i.e. complaints of tingling, decreased range of motion, a swollen body part usually a joint, an area of the body that is warm to the touch, child favors a limb or refuses to use a limb, limps, ect.)
 - Nutrition and eating patterns
 - Exercise and physical activity
 - Current medications/any side effects or reactions
 - Known food and/or drug allergies
 - Height and weight, plot on growth curve
- Encourage testing as recommended by the American Pediatrics Assoc. (APA)
- School performance and behavior
- Encourage family and child to live as "normal and active" life as possible

Contact CSH if family is Non-Compliant (i.e. repeated missed appointments, failure to follow healthcare plan)

• **Referrals** that may be recommended (CSH prefers Pediatric Specialist, if possible)

Visits to Providers may be limited due to budget

- Geneticist
- Hematologist
- Mental Health
- Link the child and family with appropriate and needed services (Hemophilia treatment ranks among the most expensive chronic diseases in the US, financial resources and referrals would be greatly needed in some cases)

Specialists may or may not be covered by CSH Program

7/2006 Bleeding Disorders 2006

• Well Child Checks

- Immunizations (including vaccinations)
- Assess and follow-up any abnormal findings
- Dental
- Vision
- Hearing

• Emergency Preparedness Plan

- Medic Alert ID bracelet / necklace should be encouraged
- Medical Emergency Plan of what to do for the child's care when away from home or with a
 different caregiver (i.e. contact information in the event of an emergency or the child suffers a
 blow to the head, neck, or abdomen, how to identify when the child might have a bleed, pay
 close attention to the child and how he/she feels, they are very knowledgeable about how they
 feel when a bleed is occurring)
- Discuss self-management of the disease
- Encourage the family to speak with the child's school in regards to the school's policy on
 Hereditary Clotting Factor Deficiencies (Bleeding Disorders) and emergency plan (i.e. who
 will administer medical attention and alert parents when the child has suffered a blow to their
 body or extremities, who will assure child is wearing protective devices during periods of
 physical activity)

Health Record

- Encourage family to maintain a record of the child's health information ("Packaging Wisdom" as a suggestion) that includes:
 - Medicine administration
 - Type
 - Dosage/Frequency, any side effects or response to medication
 - Track each instance of bleed
 - The cause of the bleed
 - Duration
 - Amount
 - How the child felt when the bleed was occurring
 - Blood-Bourne viruses
 - Treatment/procedures and hospitalizations
 - List of providers and contact information, if available

• Transition

Refer to the Care Coordination Manual, Ch. 3, Pg. 10, Coordinating Care

- Discuss with the family if the child is eligible for an IFSP, IEP, or qualify for Section 504 according to the American Disability Act (ADA)
- Social Security Supplemental Income (SSI)
- Social Security Disability Insurance (SSDI)
- Financial capabilities and resources/referrals
 - Hemophilia is an <u>expensive</u> disease; parents should fully understand their insurance
 policies and ask specific questions regarding pharmaceutical coverage and costs,
 lifetime cap amounts, and exclusionary riders

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